

Direct Care Alliance Policy Brief No. 4

Supporting Direct Care Workers in Caring for Aging Lesbian, Gay, Bisexual, Transgender Individuals

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I. Introduction

According to *Improving the Lives of LGBT Older Adults, March 2010*, three unique circumstances make successful aging difficult for lesbian, gay, bisexual or transgender (LGBT) individuals:

- > The effects of social stigma and prejudice, past and present.
- ➤ Reliance on informal families of choice for social connections, care and support—at a time when government and other institutions largely define "family" based on marriage and biological kin.
- ➤ Inequitable laws and programs that fail to address, or create extra barriers to, social acceptance, financial security, and better health and well-being for LGBT elders.^{i, ii}

Long-term and home care are characterized by gaps in care, barriers to continuity of care, provider unresponsiveness, and multiple missed opportunities in preventing health care complications. These factors contribute greatly to costly emergent care for the aging and disabled. The more disconnected individuals are from service providers, the more likely they are to fall through multiple delivery cracks, age with complications, and die alone.¹¹¹ Discrimination, stigma, inequitable laws and insensitive care are, by their very nature, blinders to appropriate care delivery and add to the costs of care for most minorities due to unnecessary and repeated hospitalizations.

Direct care workers—nursing assistants, home health and home care aides, direct support professionals and other hands-on caregivers—provide assistance with crucial activities of daily living (bathing, dressing, toileting, eating, and transferring). This workforce enables millions of Americans—through a myriad of intimate gestures and efforts—to maintain their dignity, independence, and involvement in community; to work; and participate in social activities. Direct care workers are often the first to notice a change in a consumer's physical or mental status, serving as the eyes and ears of the long-term care system and providing a crucial—though often overlooked—link between consumers and their nurses, doctors and other licensed caregivers.

However, direct care workers are often unacknowledged in their roles in the health care system. They are routinely underpaid and under-appreciated by the industry that employs them. They are often the main repositories of discretion,

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The Direct Care Alliance

The Direct Care Alliance is the national advocacy voice of direct care workers. We empower workers to speak out for better wages, benefits, respect, and working conditions, so more people can commit to direct care as a career. We also convene powerful allies nationwide to build consensus for change.

compassion, kindness and vigilance within the health care setting, and cut down on costs by making care more appropriate and adequate for consumers.

A strong solidarity often exists between direct care workers and lesbian, gay, bisexual, transgender individuals in the undervaluing that takes place culturally with respect to their abilities, needs, and rights to be protected equally in the workplace and in civil life. However, direct care workers' lack of training, empowerment and respect can negatively affect the quality of care they are able to provide to LGBT elders.

This briefing paper is an overview of lesbian, gay, bisexual or transgender (LGBT) elder issues in long-term care institutions, community care and home care. The briefing paper's aim is to demonstrate how the cultural and legal landscape negatively affects the health of LGBT seniors, and direct care workers' role in improving the quality of service to LGBT elders.

This paper draws from the recent emergence of policy briefs and agency documents outlining the concerns of LGBT stakeholders, as well as recent infrastructure changes in long-term care payment through Medicare and Medicaid that allow LGBT individuals the opportunity to remain in welcoming communities and environments.

While sexual minorities share barriers to care with other minorities, the former have barriers that heretofore have not been recognized and, when recognized, not acknowledged.

In what follows, there is ample discussion of a lessthan-welcoming environment for LGBT seniors in longterm care, as well as promising new attempts to change this through policy and laws.

II. Lesbian, Gay, Bisexual, Transgender Individuals

Four minority seniors—members of a gay, lesbian, bisexual, transgender network—died unsupported and alone in their apartments in Brooklyn in 2004, due to their inability to identify their critical medical and psychological needs to service providers, and/or to trust providers to intervene appropriately. Conventional geriatric and social service agencies in Brooklyn missed each of these individuals and were unaware that they were in distress. The community center of which they were members knew intermittently of their distress but, underfunded and without paid staff members, were unable to get them to

follow up on referrals for formal and public services. Each of the four feared that they would be mistreated because of their race, their lifestyle, their gender change or their unwillingness to join conventional programs.^{iv}

There continues to be a dearth of data on how, when and where aging services are available to LGBT elders across the country and what such services actually entail. Only one agency, Services & Advocacy for GLBT Elders (SAGE), has data directly related to federal policy with respect to long-term care and home care and to aging services in general. One study includes a survey of 24 federal Area Agencies on Aging that showed nearly 1 out of 2 respondents (46%) reporting that openly LGBT seniors would not be welcome at senior centers in their areas; 96% of them offered no LGBT-specific services. Another study of provider knowledge of aging services involved 25 key informant interviews at town hall meetings held in five U.S. cities: Bangor, Maine; Boston, Massachusetts; Seattle, Washington; Chicago, Illinois; and Fort Lauderdale, Florida, vi as well as an online survey reaching more than 509 individuals and providers having knowledge of LGBT communities, aging issues, health care and community-based organizing.

As Table 1 indicates, few LGBT services were judged

Table 1: Sensitive Service Available

Source: *National Needs Assessment and Technical Assistance Audit*, www.MarijPlumb.com/pdfs/SAGE, 2003

Aware of LGBT Sensitive Mainstream Services in Their Own Community	Key Informant Interviews (n=22)	On-Line Survey (n=509)
Home Care Services	45%	17%
Religious or Spiritual Services	41%	36%
Mental Health Services	36%	31%
End of Life/Hospice Care	36%	26%
Legal Services	41%	25%
Social Activity Programs	41%	22%
Case Management	36%	19%
Meal Sites/Nutrition Programs	36%	18%
Care Giver Support Services	36%	17%
Senior Center	36%	17%
Senior Housing	36%	13%
Transportation	27%	12%
Adult Day Health Programs	27%	11%
Elder Abuse Programs	36%	11%
Employment Programs	27%	6%

to be available by these surveys. Even when services are available, most LGBT individuals, especially low-income and racial/ethnic minorities, do not participate. As a result, a wide gap in service utilization exists between LGBT individuals and non-LGBT individuals.

This National Needs Assessment and Technical Assistance Audit, the only one of its kind, had the following chief findings:

- "In a country with a high penetration of LGBT community centers, AIDS service providers, gay-straight school alliances, and programs for LGBT youth, there is a severe shortage of specific and sensitive services for LGBT elders.
- Most LGBT elders do not believe they are, or would be, welcome in mainstream senior service programs, or that such programs would be sensitive to their needs and life experiences.
- LGBT seniors of color as well as transgender elders feel unwelcome even among other LGBT elders; many view existing programs to be hostile to their participation."vii

As they age, many LGBT elders retreat into invisibility, reinforcing their isolation and endangering their overall health. LGBT seniors who belong to other racial and ethnic minority groups are especially under-served due to the layered discriminations that already exist among these populations. There are also relatively fewer options for alternative programs due to a lack of financial support. The transgender population is particularly vulnerable to being viewed as pathological by the medical profession. They may be stigmatized due to the surgical and hormonal alterations made to their bodies, their concerns about gender, or actions they have taken or contemplated with respect to their gender identity. The recommendations offered at the conclusion to this paper are directed to the transgendered individual, but may be tailored for other members of the LGBT community.

In the last five years, the landscape for LGBT care has begun to change, thanks to LGBT organizations that have successfully advocated for mainstream organizations to address LGBT elder needs. Groups like the American Society on Aging and AARP have added specific resources and language around LGBT-affirming positions on elder services. The Joint Commission on Long Term Care, which regulates assisted living and nursing care facilities, issued regulations against LGBT bias in 2006, which are now being sporadically enforced. And very recent major health

care policy gains from the White House for LGBT elders include the following notable developments:

Presidential Memorandum-Hospital Visitation for Gay and Lesbian Americans, April 15, 2010. The language was especially notable for its directness and humanity...

"All across America, patients are denied the kindnesses and caring of a loved one at their sides—whether in a sudden medical emergency or a prolonged hospital stay. Often, a widow or widower with no children is denied the support and comfort of a good friend. Members of religious orders are sometimes unable to choose someone other than an immediate family member to visit them and make medical decisions on their behalf. Also uniquely affected are gay and lesbian Americans who are often barred from the bedsides of the partners with whom they may have spent decades of their lives—unable to be there for the person they love, and unable to act as a legal surrogate if their partner is incapacitated."

U.S. Department of Housing and Urban Development issued LGBT nondiscrimination regulations in publicly-funded housing (June 7, 2010), with explicit language

funded housing (June 7, 2010), with explicit language redefining "family" so that LGBT families do not face impediments to qualifying for HUD programs.^{ix}

U.S. Department of Health and Human Services Secretary Kathleen Sebelius established the first National Caregivers Resource Center (June 14, 2010) catering specifically to LGBT seniors, making possible a collaborative \$900,000 grant over three years to 10 partner agencies around the country from HHS and the Department for the Aging.*

The Older Americans Act, Title III (2009) updated language in the reauthorization of the Act, extending the definition of caregiver beyond legally married spouses and blood relatives. This change enables members of LGBT chosen families to qualify for benefits.^{xi}

There are still major changes that must be made in our culture, laws, policy and senior care services in order for LGBT elders to reach parity with their non-LGBT counterparts. The goals in aging for sexual minorities are the

same as the goals of heterosexual elders. Put succinctly by a transgender elder activist:

"We human beings want, generally, the same things: respect, choice, human connection, to be valued."xii

According to a philanthropy network committed to increasing the awareness of LGBT needs across the philanthropic networks, "successful aging" for LGBT elders includes the abilities or support to:

- > Maximize one's physical and emotional well-being throughout the aging process.
- > Maintain the highest possible degree of autonomy and independence for as long as possible.
- > "Age in place" in one's own neighborhood or community, within a context of respect, safety, and support.
- > Remain actively engaged with social networks, including chosen and biological families.
- > Pursue the social, recreational, intellectual, spiritual, and creative activities that provide a sense of stability, fulfillment, and vibrancy throughout the life cycle.xiii

Table 2: How to Close the Disparities Gap

Source: Jeff Krehely, Center for American Progress, pg. 3xiv

IMPACT OF SOCIETAL BIASES ON MENTAL HEALTH AND WELL-BEING

■ Heterosexual ■ LGB ■ Transgender

Health Disparity #11: LGB adults are more likely to experience psychological distress.

% of adults experiencing psychological distress in past year



Health Disparity #12: LGB adults are more likely to need medication for emotional health issues.

% of adults needing medication for mental health



Health Disparity #13: Transgender adults are much more likely to have suicide ideation.

% of adults reporting suicide ideation



Health Disparity #14: LGB youth are much more likely to attempt suicide.

% of youth reporting suicide attempts



The goals include the specific needs for accessible and comprehensive health services, prescription drug coverage, and long-term or home care that reflect safety and comfort in a home integrated within a community context.

LGBT elders suffer from elevated health risks, less access to adequate housing, and higher levels of poverty, in tandem with an extremely limited awareness of possible avenues of aid.xiv Individuals who are both LGBT and members of a racial or ethnic minority face the highest level of health disparities and access to care. For example, a black gay man faces disparities common to the African-American community (such as poverty and lower education achievement) as well as those suffered by the LGBT community. A transgender Spanish-speaking woman, regardless of her sexual orientation, must navigate multiple instances of discrimination based on language, ethnicity, and gender. A report detailing the increased jeopardy of LGBT individuals in racial and ethnic minorities is aptly called "All of the Above: LGBT People of Color."xv

With the added jeopardy of layered discrimination comes higher rates of mental health and emotional distress. Table 2 demonstrates that there are mental and physical consequences to living as a stigmatized individual.xvi The needs of LGBT individuals are highly varied and individuated for each sexual minority. However, they are largely hidden and represent shared needs of LGBT seniors who have been frightened away by racism, sexism, ageism and homophobia, and who have traditions of not conforming to conventional norms or expectations. These are needs largely overlooked and/or misunderstood by traditional senior service providers, and they offer opportunities for training, experience, and increased sensitivity and refined policy by traditional providers.

All elders—whether LGBT of not—face fears at the prospect of being confined to a nursing home or other long-term care facility. They worry about being disconnected from their community and social network, or attended by a disapproving worker as they find themselves experiencing diminished autonomy.

But this fear is even more pronounced among LGBT elders, who have endured discriminatory treatment at the hands of society and traditional institutions for decades because of their sexuality and/or gender.

While all elders share social invisibility due to ageism, racism, sexism, and/or discrimination against people with disabilities, LGBT elders face another layer of invisibility that severely complicates the quality of their lives and their aging options within the purview of health care and housing. If their sexuality is acknowledged, they may face discrimination. But if it is not acknowledged, they may be denied a key part of the identity that defines them, their loved ones, and their families, which affects the kind of care they need.

Sexual invisibility, while oppressive to all elders, both in institutional policy and in community attitudes, has broad implications for LGBT individuals. Numerous articles and studies on LGBT elders describe widespread prohibitions on same-sex partners living together in elder care and senior housing facilities. An abundance of anecdotal information from service providers and LGBT agencies describe anti-LGBT bias in nursing homes and by community-supported providers.

In a survey of social workers in New York State nursing homes conducted in the mid-1990s, the majority (52 percent) reported intolerant or condemning attitudes toward lesbians and gay men. Of the 29 nursing homes represented in the study, only one offered formal training to staff on sexuality and the rights of residents to express themselves sexually.^{xvii}

LGBT elders in relationships face an additional layer of discrimination, since their relationships, until this year with President Obama's Executive Order, have never been formally recognized nor legally protected in institutional care settings. *Viii Until this order is enforced at the frontline of care, these seniors face the risk of being denied the visitation privileges that non-LGBT spouses enjoy; and also risk being separated from their partners and forced to live apart in a separate nursing home or housing facility.

III. Lesbian, Gay, Bisexual Transgender Individuals: What We Know and What's Left to Learn

Lesbian, gay, bisexual and transgender individuals are sexual minorities about which we know little. They are largely invisible because large national studies, such as the CDC's National Health Survey, don't gather data on an individual's sexual orientation or gender identity. In 1990, the US Census began counting same-sex couples, and included relevant questions in its 2007 survey.*ix Because we don't have a national LGBT census, it is more difficult to collect data on these individuals in institutions and in

communities, and we must rely upon advocacy agencies for the information. Comparatively, it would be like the NAACP acting as the only source of national or state information on the lives of African Americans. While LGBT agencies have provided most of the information and spend a sizeable portion of their nonprofit budgets continuing to do so, the lack of government data speaks volumes about how little governmental and cultural parity LGBT concerns have compared to other American groups.

According to the National Gay and Lesbian Taskforce, 12.6 percent (38 million people) of the U.S. population is over the age of 65. This number will nearly double by 2030, when there will be 72 million over 65. Since the LGB population is estimated to be between 5–10 percent of the general population, this means that today, 1.4 to 3.8 million LGB Americans are reaching standard retirement age, with an estimated 3.6 to 7.2 million projected to be 65 or older in 2030. The number of transgender elders is completely unknown.*x

Older individuals are largely closeted, even to their health care providers, because they were young adults during a period when people could lose their jobs or be committed against their will to a mental institution if their sexual orientation was known. As late as the 1990s in some states, people could be arrested for being involved sexually with someone of the same sex or for dressing entirely in clothes of the other gender. Until the U.S. Supreme Court's 2003 ruling, some states maintained laws against sodomy.

Hiding one's sexuality is a lifelong survival strategy that elders in their 60s, 70s and 80s "still carry with them when seeking long-term care, entering a nursing home, or speaking with a health care provider." According to a MetLife study of 1,000 LGBT elders across the U.S., discrimination was the greatest concern about aging for 32 percent of gay men and 26 percent of lesbians. Those in partnerships feared discrimination the most, and twenty percent had little or no confidence that health care providers would treat them with dignity and respect. XXIII

According to *Improving the Lives of LGBT Older Adults, March 2010*, the typical lesbian, gay, bisexual, or transgender elder is well-educated, middle class, employed, and in a committed relationship. Almost a third are completely closeted. Almost 50 percent (44%) are "out" and publicly acknowledge their relationship/sexuality.^{xxiii}

"Closeted individuals" means that elder care housing and care providers are not aware that they are serving LGBT seniors. This increases their invisibility and the lack of response to their needs. Further, it perpetuates the myth that these settings are not humane and not ones in which to live open lives. "Out individuals," many of whom are also "baby boomers," may change this atmosphere in the coming years. They have lived most or all of their lives "out of the closet" and increasingly demand more accountability and responsiveness to their needs within elder care and in service settings of all kinds."xxiv The benefits of openness and activism have resulted in better social networks, awareness by agencies of the need for more research and data, and an understanding of social support for all minorities.

One major strength of the LGBT population is its tendency to establish communities that supply networking opportunities and a variety of crucial social supports, including care-taking and social connection. Such communities in large cities are geographical magnets, housing a predominant sector of LGBT individuals who have undergone displacement from their towns and cities due to local hostility to their sexuality or gender options. These strengths have increased the existence of LGBT-friendly long-term care facilities for those who can afford them, and offer new possibilities as local communities that can benefit from Medicaid waivers for "aging in place."

In the MetLife study, one in five LGBT individuals expressed concern about who would care for them when the need arose. Those without a partner expressed the most fear for themselves in the future.xxvi Almost one-quarter were caregivers for parents, for partners (18%) and friends and nonrelatives (26%), and many expressed expectations to be a caregiver for a friend or family in the future (75% to 80%). Finally, LGBT elders report an almost universal fear and anxiety about care provision by strangers in assisted living and nursing home settings.

IV. Embarking on Appropriate Long-Term, Community and Home Care for LGBT Individuals

As Table 1 indicates, LGBT individuals require the same kinds of specific care that non-LGBT individuals require. However, unless their sexuality and/or gender are recognized, service delivery for specific needs will certainly fail them. "Invisible clients" are those whose sexuality or

gender history differentially affects their needs for accurate intake; family involvement; case management; housing; social activity; recreation and creative efforts; spirituality; visitation; basic safety and care; community support; and hospice care. While "out" clients are at risk for maltreatment, "closeted" clients are at risk for irrelevant care stratagems. But neglect of their needs in the blur of heterosexual assumption and practices is not the only harm. In fact, neglect based on discrimination stigmatizes the individual and severely increases their likelihood of mental health deterioration and depression.xxxii

There are two avenues of redress for the care of LGBT seniors in the quest for appropriate and respectful care. Both alternatives will be needed.

1. Increase alternatives in care, utilizing LGBT settings and LGBT-based long-term care organizations. This can be accomplished by funding segregated residential living arrangements, administered and staffed by LGBT workers and/or LGBT-friendly staff. This can also be accomplished by allowing LGBT individuals to "age in place," and increasing Medicaid waivers to that end. (See discussion in endnote xxv).

"Staying in the community" means something quite different to LGBTs compared to other individuals because "communities" literally offer protection, sociality and family for LGBT individuals who are often virtual refugees from their original hometowns. They utilize their community of friends and "family" as a refuge, often in big cities, from a larger, often openly hostile environment. Staying in the community will likely be a highly meaningful solution for LGBT care, and one where direct care workers will have a prominent role in helping LGBT individuals to age while maintaining those relationships they've worked so hard to develop.

2. Implement changes in the institutional and cultural environment through new laws, enforcement of old laws, outreach, programming and training.

As we take on policies and programs supporting both alternatives, it is important to understand two principles that underlie our efforts to support direct care workers in their care of aging LGBT individuals.

Principle 1: Make an effort to truly understand bias, prejudice and discrimination and their sources.

Discussions and training on the needs of lesbian, gay,

bisexual and transgender elders are difficult because of the silence that accompanies the issues, engendering and supporting social myths. Much of the misinformation around LGBT issues is fueled by the lack of cultural discussion, and a general lack of personal knowledge by non-LGBT individuals about gay and transgender life. Some harmful stereotypes have currency in a highly volatile cultural debate, such as: "gay and lesbian individuals are wealthy and self-centered," "gay and lesbian individuals are highly-sexed and don't participate in long-term relationships," and "gays and lesbians are constantly trying to recruit the young to join them."

Introducing the facts of LGBT life and elder needs can make for highly polarized and deeply uncomfortable encounters given the politicization of the debate at the national level surrounding gay rights, gay adoption and, now, gay marriage. **xix** In general, that debate has lessened in polarization, with the latest polls indicating that 78% of Americans believe that gays and lesbians should have the same rights as everyone else. **xix** However, where there are pernicious profiles of gay and lesbian life in long-term or home care, these are exacerbated by a general difficulty and discomfort that direct care workers feel when sexuality becomes a part of training.

Prejudice is an individual attitude, but its source is usually not just individual opinion. Aging, sexism, and heterosexism are systemic and cultural events. After all, it is culture that first forms most of the views we have of human characteristics and behavior.

Prejudice is systemic until laws change the environment for social attitudes. It will exist until policy makes it easy for people to change their attitudes and embrace the humanity and dignity of individuals they encounter through friendship, family, church or other forms of institutional regard.

The burden of enlightenment and respect for others does not fall solely upon us as socially embedded individuals. However, we are responsible for finding starting points to reaching tolerance and seeking information about the truth of groups and communities that society may intermittently stigmatize.

Ageism is a perfect example of misinformation and myth instigation. We dispel misinformation and bias by becoming acquainted with the aged and discovering their individuality, their needs, their strengths, and their creativity. These changes in viewpoint occur most easily when we are required to change our views and are given opportunities and information that make this possible.

Some of the policy that makes LGBT prejudice so prevalent in the health care context begins at very high levels, starting with the lack of data collected by national agencies on the facts about gay, lesbian, bisexual and transgender lives. Myth cannot be dispelled without data. And, as a culture, we are just now beginning to document the facts about LGBT individuals.

At the policy level: Without proper data about the lives of LGBT individuals, there cannot be effective policy related to their needs. Much more data collection and research is required, but even with the data we do have indicating the large disparities in health status, access and utilization of health care, policymakers at the federal levels cannot "level the playing field" for LGBT without acknowledging that they have unique needs.

At the individual level, where we are motivated to be sensitive to needs that we do not always understand, tips on language, gesture and bearing with clients are a great help. Table 3 offers a short sheet of recommendations for working with transgender individuals. It can also be modified for lesbian, gay or bisexual individuals. But remember, LGBT individuals often are not comfortable revealing their sexuality in a long-term care setting, so "teachable moments" for providers who make the mistake of saying or doing something disrespectful may not occur as easily with LGBT individuals as they would in caring for members of minority groups that are not "invisible" in potentially hostile environments.

Principle 2: Short-Term "Cultural Competence" is Not the Answer

Underlying the need for training for specific cultural or community sensitivity and civil rights is the issue of appropriate health care delivery, which can target delivery to the most vulnerable and hard-to-treat patients.

Our health care system has segmented populations and individuals into risk groups and payment segments without overall policy mandating equitable treatment for all. This leads to the isolation of vulnerable groups, forcing them to compete for attention from the health care system and leaving them vulnerable to attack as self-serving for seeking equality and respect. A universal bill of rights for everyone within the health care system that can respond to the needs of the most

Table 3: Transgender Cultural Competence for Medical/Clinical Settings

Source: Renata J. Razza, Trainer*xxi (edited)

GENERAL INFORMATION

- > Sex refers to biology and anatomy.
- ➤ Gender refers to identity (how someone understands who they are), expression (how they show the world their identity) and cultural roles (societal expectations of us).
- ➤ Anatomy, identity and behavior can be arrayed in a multitude of ways.
- Many LGBT people have experienced invisibility, disrespect and/or have been pathologized by the medical establishment in addition to experiencing discrimination and violence in their daily lives.

ESTABLISH A RAPPORT OF RESPECT

- ➤ Offer care as you would for anyone: Introduce yourself warmly. Get to know the person.
- Respect each individual's gender identity, even if it doesn't make sense to you.
- ➤ Use the pronouns and name the individual uses and prefers.
- Ask only questions relevant to the care you offer; do not ask questions to satisfy your own curiosity.
- ➤ Invite the patient to share language about body parts and activities that works for them.
- ➤ Be mindful of your assumptions: avoid assuming anatomy based on gender identity and vice versa.
- Admit when you don't know and respectfully ask for the patient's help.
- > Apologize, but don't over-apologize for mistakes.
- ➤ Do not assume all people of transgender experience want to talk about being transgender.

USEFUL QUESTIONS AND WORDING

- > What is your pronoun preference?
- ➤ What name may I call you? or Is that the name you prefer to be called?
- > Please describe your gender identity.
- > What genders are your sex partners?
- ➤ To my knowledge, I haven't had a transgender patient before. I want to be respectful and offer you excellent care. Please let me know if there is anything you think I should know or that you would like me to know that will help me provide excellent care for you today.**xxii

NOTE: An extensive set of recommendations, discussion and tips (best practices) for working with transgender individuals can be found at agencies directed at youth. This is where much of the educational work in countering LGBT prejudice has been directed.

vulnerable, hard to reach and hard to treat individuals would serve as a foundation for all other groups. Such a bill of rights would make "cultural competence" a term of inclusion for more refined responses dictated by optimal care, not by basic care. xxxiii

During the most frightening period of the HIV/AIDS epidemic, the New York City Commission on Human Rights was repeatedly asked to help design **special protections for health providers** to minimize the risk of infection. It had to be pointed out repeatedly that "standard precautions" (which became "universal precautions" issued by OSHA, 1986) generally in place since the 1880s in health care were adequate for any health care professional, requiring no new protocols or measures; that standard precautions, reframed as "universal precautions" are exactly that, directed at every typical and atypical source of infection. "XXXIV To satisfy agencies and practitioners, the Commission offered training to convince wary providers that these precautions were sufficient.XXXXV

The latter point is important. The disability community has taught us that innovations designed to lower barriers to care for those living with a disability have merged or morphed into some of the most important and widely used improvements to the system. However, unless such innovations are known to policy makers, planners and supervisors, and implemented at the frontlines, direct care staff must make up their own stratagems for dealing with the atypical client. And this shortsightedness makes "cultural competence" only a narrow victory.

V. Recommendations for Policy Makers, Associations and Administrations

Recommendation 1

Advocate for generic laws for determining education, respect and support for empowering the most vulnerable individuals, responding to their health needs, protecting their safety and dignity, and build from there.

Recommendation 2

Internally, align your agency, your state worker association and/or your facility with the laws concerning your clients at the federal, state and local levels. Four large federal initiatives are outlined in the Introduction to the

paper. Make sure that your institution is in compliance with all four.

Using the attached guide to state laws in Appendix I, ensure that your institution is in compliance with your state, and where possible, your county and city laws related to LGBT civil and health rights. If you are unclear about your state and local laws, ally yourself with a local chapter of SAGE, the National Gay and Lesbian Taskforce, or with the ACLU, and seek guidance on which laws are applicable in your care for LGBT seniors. These agencies are more than happy to help and to be partners in redressing the needs of LGBT seniors.

Recommendation 3

Develop LGBT programs and training. To establish a program or training for LGBT sensitivity and relevance, form an organization-wide taskforce and take the following steps.

- **1.** Establish an office or enforcing committee for LGBT health, with accountability that reaches all the way up through the agency to officers of the organization.
- **2.** Convene a strategic planning committee to develop guidelines for LGBT anti-discrimination and training for respectful and lawful treatment of sexuality minorities. As your initial task, determine answers to the three levels of inquiry outlined in Table 4.
- **3.** With any new program for responding adequately and relevantly to the needs of a community, the mantra is:
- A. Assess
- B. Engage
- C. Plan
- D. Develop a Program
- E. Evaluate

Assessment:

Provide your agency, association, or facility with the tools necessary to assess your organization's ability to recognize and respond to LGBT rights and needs. This is best done by engaging in a partnership with LGBT-serving aging institutions or with the local chapter of a national LGBT advocacy agency.

Initially assess your facility for LGBT-friendly procedures, from outreach/inclusion at the front door throughout the range of your services, utilizing Table 1.

Table 4: Levels of Inquiry

Suggestions utilized from the Open Door Taskforce Training Program of the LGBT Aging Project in Massachusetts, www.lgbtagingproject.org

1) INSTITUTION/ORGANIZATION:

- > Is inclusion part of your organization's core values?
- How inclusive are policies for employees and consumers?
- > How inclusive are your programs and services?

2) POLICY AND PRACTICE:

- ➤ How do you convey your commitment to LGBT inclusion to your employees?
- ➤ Have you expanded the professional capacity to enhance skills/service delivery; to deal with backlash; to sustain these efforts?

3) COMMUNICATION:

- ➤ Have you educated/notified community partners and colleagues about inclusion efforts?
- ➤ Have you increased outreach to LGBT elders to build credibility and delivery of services based on inclusion?

Ask yourself "What is the LGBT content for each of these services?" For example:

Do you have paperwork that identifies partners or chosen family, as well as biological family?

Are your intake procedures careful to allow chosen family to get involved in long-term care, community care or homecare procedures?

Do you have posters that support LGBT rights? In general, find out how difficult it will be to identify LGBT clients and what role they will play in planning.

Engage With the LGBT Community:

Begin with LGBT personnel and clients, or with a local LGBT advocacy agency. If you have LGBT-identified personnel, ask them to become members of your strategic planning taskforce or stakeholder group. If you have LGBT-identified clients, align them with whatever planning initiatives you hold. Whenever vacancies arise in employment, consider hiring LGBT individuals into your workforce.

Plan: Structure planning sessions over a short period of time. Bring in outside speakers, and facilitate discussion with a highly skilled staff member whom everyone likes

and respects. Make discussion and content as transparent as possible for the whole organization, and try to focus upon short- and long-term goals. And formulate a set of outcomes that you wish to achieve.

Develop a program/training from outcomes that you wish to engender across the agency. These outcomes will become the basis for the six-month ongoing evaluation of your efforts.

Make a program and/or training highly transparent and supported by the highest officers of your organization. Bring in consultants for developing training curricula and involve the entire organization in organization-wide "kick off" event with films and a motivational speaker.

Evaluate your efforts by measuring your outcomes. Your achievements should be evaluated progressively, in a formative way, with expectations for changing your activities and even your objectives as you find out what works. A six-month evaluation and review is a good timeline. The development of an effective intervention to atypical clients, especially ones with whom some providers may be uncomfortable working, is a long and highly rewarding process. It involves successful outreach, relevant and adequate procedures and data collection, and it includes

changes in staff procedures, feeling and attitudes. Make sure that your evaluation measures changes in attitude in consumers as well as in providers, because these are the most significant and the most satisfying outcomes.

VI. Conclusion

As direct care workers find support for working with LGBT clients, and see the need for changes and accommodations, it is important to remember the inherent solidarity that exists between the needs of under-acknowledged and under-resourced direct care workers and underacknowledged and under-resourced LGBT clients. It is a truism that discrimination, stigma, inequitable laws and protections in care delivery and in the workplace are by their very nature blinders to appropriate care delivery. As direct care workers advocate for their own acknowledgement and legal and monetary protections, they can be stronger advocates for clients that are burdened with the same "invisibility." Reforms that end inequity in law and benefits, that help to end stigma, lack of respect, and lack of trust support both the community of workers and their clients and benefit the health care delivery system as a whole.

VII. Appendix

Table 5: State Laws-LGBT Aging State-by-State

LGBT elders face more hardships than just the barriers created by lack of entitlement to Social Security Survivors Benefits, punitive Medicaid policies and the Defense of Marriage Act. LGBT elders are affected every day at the state level. For a list of state laws affecting LGBT individuals, see Table 5 from the OutingAge 2010** (a reissue of the landmark National Gay and Lesbian Taskforce 2000 report). For state-by-state discussions, utilize the National Gay and Lesbian Taskforce's Our Maturing Movement: State-by-State LGBT Aging Policy and Recommendations, 2010.**

		State has Non- Discrimination Law, Sexual Orientation	Discrimination Law,	on Aging has Age Non-	State Office or Division on Aging has Sexual Orientation Non-Discrimination Policy	State Office or Division on Aging has Gender Identity Non-Discrimination Policy
Alabama	YES	NO	NO	NO	NO NO	NO
Alaska	YES	NO	NO	NO .	YES	NO NO
Arizona	YES	NO	NO	NO	NO NO	NO NO
Arkansas	YES	NO	NO	NO	YES	NO
California	YES	YES	YES	NO NO	NO NO	NO NO
Colorado	YES	YES	YES	YES	YES	NO NO
Connecticut	YES	YES	NO	NO	NO	NO
Delaware	YES	NO	NO	NO NO	NO NO	NO NO
District of Columbia	YES	YES	YES	NO NO	NO NO	NO NO
Florida	YES	NO	NO	NO	NO NO	NO
Georgia	YES	NO	NO	NO	NO NO	NO NO

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(cont'd from page 10)

State	Discrimination	State has Non- Discrimination Law, Sexual Orientation	State has Non- Discrimination Law, Gender Identity	on Aging has Age Non-	State Office or Division on Aging has Sexual Orientation Non-Discrimination Policy	State Office or Division on Aging has Gender Identity Non-Discrimination Policy
Hawaii	YES	YES	YES	NO	NO NO	NO NO
Idaho	YES	NO	NO	NO NO	NO	NO
Illinois	YES		YES	YES	YES	YES
Indiana	YES	NO	NO	NO NO	NO	NO NO
Iowa	YES	YES	YES	NO	NO	NO
Kansas	NO	NO	NO	NO NO	NO	NO
Kentucky	YES	NO	NO	NO NO	NO NO	NO NO
Louisiana	YES	NO	NO	NO	NO	NO NO
Maine	YES	YES	YES	NO NO	NO	NO NO
Maryland	YES	YES	NO	NO NO	NO	NO NO
Massachusetts	YES	YES	NO	NO NO	NO	NO
Michigan	YES	NO	NO	NO NO	NO	NO NO
Minnesota	YES		YES	NO NO	NO NO	NO NO
Mississippi	• NO	NO	NO	NO	NO NO	NO NO
Missouri	YES	NO	NO	NO NO	NO NO	NO
Montana			NO	NO	NO NO	NO
Nebraska	NO	NO	NO	YES	NO	NO NO
Nevada	YES	YES	NO	YES	NO	NO NO
New Hampshire	YES	YES	NO	YES	NO NO	NO
New Jersey	YES	YES	YES	NO	NO	NO NO
New Mexico	YES	YES	YES	YES	YES	YES
New York	YES	YES	NO	NO	YES	NO
North Carolina	YES	NO	NO	YES	NO NO	NO NO
North Dakota	YES	NO	NO	YES	YES	NO
Ohio	YES		NO	YES	YES	NO
Oklahoma	YES	NO	NO	YES	NO	NO NO
Oregon	YES	YES	YES	NO NO	NO	NO
Pennsylvania	YES	NO	NO	NO	NO NO	NO
Rhode Island	YES	YES	YES	NO	NO	NO NO
South Carolina	YES	NO	NO	YES	NO	NO
South Dakota	NO		NO		NO NO	NO NO
Tennessee	YES		NO	YES	NO NO	NO NO
Texas	YES	NO	NO	•	NO NO	NO
Utah						NO NO
Vermont	• VEC		YES	· NO	NO.	NO
Virginia	YES	•	NO	•	NO	NO
Washington	YES	VEC	VEC	VEC	VEC	YES
West Virginia	YES		NO	• 110	• • • • • • • • • • • • • • • • • • • •	NO
Wisconsin	YES	•	NO	•	•	NO
Wyoming	YES	•	NO	•	•	NO

NOTE: These non-discrimination laws and policies do not establish uniform protections. Areas of protection might include employment, public accommodations, housing, education, real estate, credit, insurance and health maintenance organizations. Please see individual states' law codes for details.

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Confronting Health Care In The United States (Penguin), and has worked for over fifteen years as a consultant to non-profit agencies and community based programs. Website: www.NPOCentral.net/NancyMckenzie, Email: nmckenz@hunter.cunv.edu or Nancy.Mckenzie@comcast.net.

End Notes

Produced by SAGE (Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders) and the LGBT Movement Advancement Project (MAP), the report, co-sponsored by the Center for American Progress, the National Senior Citizens Law Center (NSCLC), with a Foreword by Tom Nelson, Chief Operating Officer of the American Association of Retired Persons (AARP), is one of two of the most up-to-date and comprehensive treatment s of issues facing LGBT elders. http://sageusa.org/uploads/Large%20Print%20Advancing%20 the%20Lives%20of%20LGBT%20Older%20Adults.pdf

The other report is "Outing Age, 2010" by the National Gay and Lesbian Taskforce: www.thetaskforce.org/downloads/reports/reports/outingage_final.pdf

Both documents can serve as valuable resources for agencies and policy makers.

- According to the National Gay and Lesbian Taskforce, federal programs designed to assist elderly Americans can be ineffective or even irrelevant for LGBT elders. Several federal programs and laws blatantly treat same-sex couples differently from married heterosexual couples. For example:
 - Social Security pays survivor benefits to widows and widowers but not to the surviving same-sex life partner of someone who dies. This may cost LGBT elders \$124 million a year in un-accessed benefits.
 - Married spouses are eligible for Social Security spousal benefits, which can allow them to earn half their spouse's Social Security benefit if it is larger than their own Social Security benefit.
 Unmarried partners in lifelong relationships are not eligible for spousal benefits.
 - Medicaid regulations protect the assets and homes of married spouses when the other spouse enters a nursing home or longterm care facility; no such protections are offered to same-sex partners.
 - Tax laws and other regulations of 401(k)s and pensions discriminate against same-sex partners, costing the surviving partner in a same-sex relationship tens of thousands of dollars a year, and possibly more than \$1 million during the course of a lifetime.
 - Even the most basic rights, such as hospital visitation or the right to die in the same nursing home, are regularly denied samesex partners.
 - Many LGBT elders experience social isolation and ageism within the LGBT community itself. http://www.thetaskforce.org/issues/ aging/challenges
- Medicare and Medicaid In Long-Term Care, Terence Ng, Charlene Harrington, and Martin Kitchener Health Affairs, 29, no. 1 (2010): 22-28.
- This is an all-too-frequent occurrence for LGBT community groups. According to Glenn Francis, Executive Director of GRIOT Circle, LGBT community organizations have formidable tasks in trying to under-

- stand how to reach out to elders, especially in communities of color. Agencies like Brooklyn's GRIOT Circle work to alleviate isolation and fear, encourage self-empowerment and honor elders' distinctive histories and traditions. www.griot.org
- Rising to the Challenge on LGBT Aging, Summary, SAGE'S STRATEGIC PLAN 2008-2012: http://www.sageusa.org/uploads/SAGE%20Strategic%20Plan.doc.
- Each meeting drew from 40-60 individuals, and included individuals representing both mainstream aging service providers and LGBT aging service providers primarily having knowledge LGBT Communities (47%), Aging Issues (45%), Health Care (30%), and Community-based Organizing (21%). The conclusions were developed as a National Needs Assessment and Technical Assistance Audit November 2003 Prepared for Senior Action in a Gay Environment Majorie Plumb Associates http://marjplumb.com/pdfs/SAGE%20National%20 Needs%20Assessment.pdf.
- vii Plumb, M. National Needs Assessment and Technical Assistance Audit, Op cit., #vi.
- viii This is from the introduction to Presidential Memorandum—Hospital Visitation Memorandum for the Secretary of Health and Human Services: Respecting the Rights of Hospital Patients to Receive Visitors and to Designate Surrogate Decision Makers for Medical Emergencies, April 15, 2010 www.kaiserhealthnews.org/Stories/2010/April/16/obama-memo-hospital-visits-document.aspx
- Notice of HUD's Fiscal Year (FY) 2010 Notice of Funding Availability (NOFA) Policy Requirements and General Section to HUD's FY2010 NOFAs for Discretionary Programs, http://www.hud.gov/offices/adm/grants/nofa10/gensec.pdf
- The National Center is charged with providing training on LGBT issues, providing access to mainstream services and providers for seniors, and critically important educational tools and information for elderly LGBT people, including financial management, case and social worker assistance, and enabling access for addressing health and disability concerns. http://phinational.org/archives/hhs-funds-first-ever-resource-center-for-lgbt-elders/
- The National Family Caregiver Support Program (NFCSP) recognizes the individuality of caregivers, the diversity of their care-giving situations and the range of their needs. The program is designed to provide unpaid caregivers with the assistance they need when they need it, so they may continue in their care-giving roles. www.aoa. gov/AoARoot/AOA_Programs/HCLTC/Caregiver/index.aspx#purpose
- The Future of Aging: Re-Defining Aging Services & Advocacy for LGBT Older Adults Plenary Presentation: No Need to Fear? No Need to Hide? Aging On Our Own Terms, Loree Cook-Daniels 2004 SAGE Conference, June 19, 2004
- diii Aging In Equity: LGBT Elders in America, Funders for Lesbian and Gay Issues, (2004) http://www.lgbtfunders.org/files/AgingInEquity.pdf, page 3
- How to Close the LGBT Disparities Gap, Jeff Krehely December 21, 2009, Center for American Progress, http://www.americanprogress.org/issues/2009/12/pdf/lgbt_health_disparities.pdf

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- All of the Above: LGBT People of Color, National Coalition for LGBT Health, 2009 http://lgbthealth.webolutionary.com/sites/default/ files/LGBT%20POC.pdf
- How to Close the LGBT Health Disparities Gap: Disparities by Race and Ethnicity, Op Cit., #xiv. Due to factors like low rates of health insurance coverage, high rates of stress due to systematic harassment and discrimination, and a lack of cultural competency in the health care system, LGBT people of color are also at higher risk for mental illnesses, and are more likely to smoke, drink alcohol, use drugs, and engage in other risky behaviors. Download LGBT race and ethnicity health disparities memo (pdf).
- xvii Social Workers' Perceptions of Sexual Attitudes of Staff Social Workers' Perceptions of Staff Attitudes Toward Resident Sexuality in a Random Sample of New York State Nursing Homes: A Pilot Study, Susan K. Fairchild; Gerard E. Carrino; Mildred Ramirez. Journal of Gerontological Social Work, Volume 26, Issue 1 & 2, October 1996, pages 153-169.
- xviii President Obama Executive Order, see above.
- xix Commercial Closet Report: U.S. Census Offers New Same-Sex Couple Data, As Research Booms, Human Rights Campaign http://www.hrc. org/Template.cfm?Section=Home&CONTENTID=19717&TEMPLATE=/ ContentManagement/ContentDisplay.cfm
- A 2000 poll by Harris Interactive reports that there are 15 million people, 6.8% of Americans, who identify themselves as lesbian, gay or bisexual, and there are more than three million same-sex couple households. http://www.witeckcombs.com/pdf/glbt-market-researchhiqhlights.pdf
- xxi Aging In Equity: LGBT Elders in America, (2004), Op. Cit, viii.
- "Still Out, Still Aging: The Met Life Study of Lesbian and Gay Baby Boomers," 2010 http://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-still-out-still-aqinq.pdf
- xxiii Ibid
- xxiv Facing Discrimination: As LGBT Long Term Care Settings are Starting to Materialize, Mainstream Facilities Must Review Their Policies and Training Programs, American Health Care Association, Provider July 2009, www.ahcancal.org/News/publication/Provider/CoverJul2009.pdf
- Older adults prefer to live in their own homes for as long as possible. In fact, it has been known for quite some time that most elders prefer that they receive needed long term care services in their home instead of in an assisted living facility or nursing home (Mattimore, R.J., et.al., Surrogate and Physician Understanding of Patients' Preference for Living Permanently in a Nursing Home, Journal of the American Geriatrics Society, 45(7), 818-24,1997). For many older adults home-based services are an increasingly popular alternative to nursing home placement that only recently has begun to receive public recognition and state regulations waivers that allow public funding to be used for this purpose. Because it has been shown that

allowing individuals to stay in their environments is also 1. more cost-effective and 2. offers more options for customized care (*Aging in Place*, Joint Center for Housing Studies of Harvard University Neighborhood Reinvestment Corporation, 2001) http://www.jchs.harvard.edu/publications/seniors/lawler_w01-13.pdf, See note 3 above.

- xxvi Op cit., #19.
- Recent studies of stress on racial minorities have revolutionized our understanding of disparities of health among racial and ethnic minorities related directly to their unequal status and the psychological effects of that inequality. See the excellent series: Unnatural Causes: Is Inequality Making Us Sick? http://www.unnaturalcauses.org/. Another, more recent a series of studies at Harvard have investigated the mental health effects of stigma on LGBT individuals and have linked their effects to depression, suicidality and psychopathology. Responses to Discrimination and Psychiatric Disorders among Black, Hispanic, Female, and Lesbian, Gay, and Bisexual Individuals. McLaughlin KA, Hatzenbuehler ML, Keyes KM.Am J Public Health. 2010 June 17
- xxviii Facing Discrimination: As LGBT Long Term Care Settings are Starting to Materialize, Mainstream Facilities Must Review Their Policies and Training Programs, American Health Care Association, Op. Cit., xxiv.
- vxx Op. cit, xv.
- http://www.renatarazza.com/images/RenataRazza_Trans101medical. pdf, See also Compliance Guidelines to Prohibit Gender Identity Discrimination, San Francisco Human Rights Commission, 2003 http://www.sf-hrc.org/index. S
- xxxxiii From the Long View: LGBT Elders and Experts Speak, Loree-Cook Daniels, The National Lesbian and Gay Taskforce, http://www.thetas-kforce.org/audio/fromthelongview/loree
- xxxxiv The use of rubber gloves became widespread after 1890, when William Stewart Halsted (1852-1922) commissioned the Goodyear rubber company to fashion gloves for his nurse to protect her hands from the mercuric chloride solutions used to disinfect the instruments. Randers-Pehrson JD: The Surgeon's Glove. Springfield, IL: Charles C. Thomas, 1960.
- xxxx Although once prophylaxis for needle sticks were possible, needle sticks for HIV/AIDS did get special protocols for immediate treatment.
- voxvoi OutingAge 2010, Jaime M. Grant, National Gay And Lesbian Task Force Policy Institute, http://www.thetaskforce.org/downloads/ reports/reports/outingage_final.pdf, page 157.
- *******i http://www.thetaskforce.org/downloads/reports/reports/our_maturing movement.pdf

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